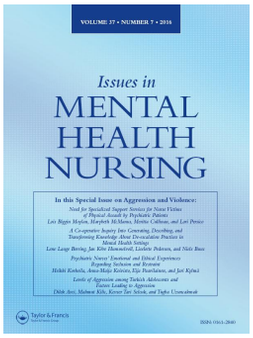

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Getting Well Is More Than Gaining Weight – Patients' Experiences of a Treatment Program for Anorexia Nervosa Including Ear Acupuncture

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ABSTRACT

This study illuminates how 25 in-patients who were treated for anorexia nervosa in a highly specialized clinic for eating disturbances in Sweden experienced the treatment program. The program included structured eating, medication, restrictions in physical activity and supportive dialogues. Patients were also offered semi-standardized NADA ear acupuncture as a complement to relieve stress, anxiety and tension. In total, 46 interviews were analysed qualitatively using latent content analysis. The results showed how participants strived with their slow transition towards recovery. The novelty of integrating acupuncture in psychiatric treatment makes this study interesting. Acupuncture was experienced to relieve anxiety and somatic symptoms through the whole process. Further research is needed to evaluate the effect of acupuncture on the patient's subjective sense of well-being when used as an adjunct to usual care.

Background

Anorexia nervosa (AN) is a serious illness with significant co-morbidity and high mortality. AN can be described as a destructive way of dealing with emotions, and anxiety is very common among persons with AN (Wildes, Ringham, & Marcus, 2010). Several other psychiatric symptoms such as depression and sleep problems, and physical symptoms like gastrointestinal issues (Fairburn & Harrison, 2003), cardiac arrhythmia and osteoporosis (NICE, 2017) co-occur in eating disorders. Recovery from AN is a long process (NICE, 2017). The evidence for psychological and pharmacological treatment in AN is weak and recommendations in national guidelines are conflicting (NICE, 2017; WFSBP, 2011). CBT is effective but expensive, in short supply and could not be offered to persons who do not want to co-operate. Medication should not be used as the sole treatment (NICE, 2017) and there is an increased risk for side effects of pharmacologic therapies in persons with AN due to the somatic comorbidities (NICE, 2017; Strober & Johnson, 2012). National guidelines recommend out-patient care as a first-line therapy setting (Hilbert, Hoek, & Schmidt, 2017). When out-patient care is not sufficient a higher level of care is needed. Sometimes even involuntary commitment and forced feeding is necessary in order to prevent starvation to death (Hilbert et al., 2017; NICE, 2017). Environmental stress, for example from being in a hospital setting and locked in, increases anxiety (Strober & Johnson, 2012). A recent systematic review (Murray, Quintana, Loeb, Griffiths, & Le Grange, 2019) including 35 RCTs evaluating a variety of treatments for AN, concluded that the interventions had a short-term effect on weight but not at follow-up, and that specialized treatments brought no advantage over comparator interventions in psychological symptoms. The findings in a meta-synthesis of 14 qualitative studies on experienced recovery from AN (Stockford, Stenfert Kroese, Beesley, & Leung, 2019) indicates that recovery is a complex psychological process. Identified themes were having a fragmented sense of self, making an active decision towards recovery after having reached a turning point and finally the process of rebuilding identity and self-acceptance.

Individualized care is important for recovery from AN (Fogarty & Ramjan, 2016; Strober & Johnson, 2012). Non-verbal, non-pharmacological treatment options with no side effects are requested both by patients (Hedlund & Landgren, 2017) and by health personnel as an adjunct to usual care to reduce symptoms (Landgren, Strand, Ekelin, & Ahlstrom, 2019). Rebuilding a healthy identity, relationships and engaging in activities that improve self-esteem have been reported as important factors for lasting recovery from AN (Stockford et al., 2019). Eating disorders impact occupational performance in many areas of life (Clark & Nayar, 2012). Occupational therapy may help in the process of recovery from AN in developing new healthy ways of doing daily occupations, finding new meaningful activities and in these build new healthy identities promoting self-esteem and lasting recovery (Clark & Nayar, 2012).

Research has shown the effect of acupuncture on neurophysiological levels. Several neurotransmitters are released and

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Clinical trial registry: In 2016, when this study opened, there was no need for registration of non-interventional studies in Sweden.

thought to be involved in the long-term beneficial effect on stress, pain and anxiety by a modulation of the limbic and related systems in the brain, shown in brain imaging studies (Dhond, Kettner, & Napadow, 2007; Fang et al., 2009). An overview of ten systematic reviews (Li et al., 2019) concluded that acupuncture had effect in the treatment of anxiety, although the methodological quality of the studies was considered as low. A branch of the vagus nerve can be stimulated by ear acupuncture, providing somatic effects. As a part of the parasympathetic nervous system, such a stimulation can affect the gastrointestinal, respiratory, cardiovascular and endocrine system as well as the smooth muscles and blood vessels (He et al., 2012). Qualitative studies confirm experiences of ear acupuncture as a beneficial treatment in psychiatric care as reported from caregivers who appreciated acupuncture as a non-verbal tool. They perceived acupuncture to be a person-centred part of the treatment, relieving patients' symptoms (Landgren et al., 2019). Ear acupuncture is considered a safe treatment with mild and transient side effects (Tan, Molassiotis, Wang, & Suen, 2014).

The standardized ear acupuncture protocol National Acupuncture Detoxification Association (NADA) was developed as an adjunct in addiction care. NADA is nowadays used as an adjunct also in psychiatric care (Stuyt & Voyles, 2016). NADA has shown effect in community mental health settings (LaPaglia, Bryant, & Serafini, 2016) and was highly utilized by psychogeriatric patients with major depression (Geib, Rieger, Joos, Eschweiler, & Metzger, 2017). Qualitative studies on psychiatric patients' experience of NADA are sparse but mediate patients' positive experiences of calm, well-being, increased energy, improved sleep and better concentration (Geib et al., 2017). Patients also described reduced craving and irritability, and reduced need of medication on demand (Bergdahl, Berman, & Haglund, 2014). A systematic review (Fogarty, Smith, & Hay, 2016) found only two RCT studies on acupuncture in the treatment of persons with eating disorder. These initial studies have shown that patients with AN may benefit from acupuncture (Smith et al., 2014; Fogarty, Harris, Zaslawski, McAinch, & Stojanovska, 2010; Hedlund & Landgren, 2017). In qualitative studies persons with AN experienced acupuncture to give an opportunity to relaxation and rest (Hedlund & Landgren, 2017; Smith et al., 2014). However, a deeper understanding of how acupuncture is experienced by patients with AN as an adjunct therapy is desirable.

Aim

The aim was to illuminate how in-patients with AN experienced the usual care including acupuncture as an adjunct therapy for stress and anxiety at a highly specialized clinic for eating disturbances.

Methods

Design

A qualitative interview study was conducted in a clinical environment. Patients' experiences were captured in semi-structured interviews. Interviews were analysed using latent content analysis (Graneheim & Lundman, 2004).

Participants and setting

Clinical experiences and existing evidence for ear acupuncture in psychiatric symptoms have led to the idea of the implementation of the NADA protocol at a specialist clinic in Sweden for persons with anorexia. The clinic serves an area with 1.3 million inhabitants and is the only in-patient clinic for adults with eating disturbances in this area. The study is a part of the ACU-EAT study in which all persons with AN treated at this clinic, independent of co-morbidities, were invited to participate. Ear acupuncture was offered as an adjunct to usual care and 25 patients who wanted to try acupuncture were included in ACU-EAT. Usual care included somatic care, structured eating, nutritional supplements, medication, restrictions in physical activity and weekly supportive dialogues with a contact person. When BMI was >16, patients could get CBT. Physiotherapy and sessions with a psychiatrist and a psychologist were offered. In addition to the usual care, participants in ACU-EAT were offered acupuncture twice a week on schedule, from inclusion for as long as they were admitted. They could ask for extra acupuncture sessions if trained staff was available. Acupuncture was provided individually, by ordinary health care staff who had a four-day training in ear acupuncture, mainly as standardized NADA treatment. Ear acupuncture points like Hypogastric plexus and Constipation, and body acupuncture points like GV20, Sishencong, Yintang and HT9 could be added to the NADA protocol. Needles stayed put for 40 min. Patients could also get acupressure from beads attached to ear points. Quantitative outcome parameters reporting utilization rate of acupuncture, patients' ratings of their subjective health in questionnaires as well as nurses' experiences will be reported elsewhere.

In total, 46 interviews were conducted with the 25 participants, all women. Their median age was 29 (range 18–72) and they were diagnosed with AN when they were median 15 years (range 7–32). Beside AN, many participants were diagnosed with depression, anxiety and obsessive-compulsive disorder (OCD). Some had been working or studying at the time for inclusion, others had been unemployed. At the time for inclusion, some had already stayed at the ward for months and were close to being dismissed. Others were recently admitted (range 0–24 weeks, median 3). Participants participated in the study for 1–26 weeks (median 9). During their stay, they received acupuncture 1–45 times (median 15). Twenty-two were admitted voluntarily and three by law. Before this admittance to hospital, participants had tried different psychiatric treatments. They had experience of paediatric psychiatry, out-patient care, day care and earlier in-patient care in substance abuse, general psychiatric or eating disorders clinics. They had met psychiatrists, physiotherapists and dieticians, and been in different kinds of therapy, and some had tried private treatment programs for AN. Some had been admitted to somatic departments or ICU for heart failure or other life-threatening symptoms due

to starvation or suicide attempts. They had a complex psychosocial situation, with a variety of overlapping psychiatric and emotional and somatic symptoms. They had been or were medicated with sedatives, antidepressants, sleeping pills and other pharmaceuticals.

Data collection

All 25 participants were interviewed at inclusion in ACU-EAT. Sixteen participants were interviewed a second time after three months, and five patients who were still in treatment after six months were interviewed a third time. The semi-structured interviews were conducted by the second author in a calm room at the ward and based on questions about their subjective health and about positive and negative experiences of the care in general and specifically on acupuncture as a complement in the treatment program.

Before the interview started information about the study was repeated. Interviews started with a broad open question, followed by questions to get a deeper understanding of the informants' experiences. Data were collected between February 2016 and May 2017.

Outcome measures

The primary outcome in ACU-EAT was patients' experience of receiving acupuncture.

Data analysis

The 46 interviews were transcribed by the second author and analysed with content analysis on a latent level (Graneheim & Lundman, 2004) which includes interpretation. The transcribed text was read through several times by the two authors to grasp a sense of the whole. It was divided into meaning units and condensed by the first author. Considering the whole context codes were outlined, labelling the condensed meaning units. Subthemes emerged from the codes, involving abstraction and interpretation of the latent content (Graneheim, Lindgren, & Lundman, 2017). During the interpretation process, we moved back and forth between parts of the text, and the whole. Subthemes merged together into themes and a main theme during reflection and long and intense discussion among the both authors until agreement.

Ethical considerations

Ethical approval from the Regional Ethical Review Board (2016/1) was received. Before giving written informed consent, students were informed orally and in writing that participation was voluntary and about the possibility to withdraw at any time.

Results

The main theme "Striving with transition to a healthy life" emerged in the analysis, along with three themes and nine subthemes (Table 1). The themes "Struggling to find a way" and "A long process towards recovery" were expressed by the participants in many different ways and represent two phases of recovery; a phase of realizing the need for help in supportive surroundings and the following phase of a slow transition towards a healthy life. The third theme, "Acupuncture adds a value" illuminates how acupuncture was experienced to relieve anxiety and somatic symptoms through the whole process. Themes and subthemes are described below and illuminated with quotes where the letter refers to the participant and the number refers to the first, second or third interview.0

Struggling to find a way

The participants described years and some even decades of illness with intense symptoms of anxiety, depression, stress, restlessness, exhaustion and inability to rest. They described how they had realized that they needed help to get back to a healthier life and the constant struggling to find a way to do so. During this process when they were searching for tools and striving with gaining weight they emphasized the importance of supportive surroundings. Participants described how the eating disorder had become a part of their identity and how the transition to a normal life was demanding. In spite of the challenge, they were determined to establish new routines. They had made a choice towards recovery.

Realizing or not realizing need for help

Patients described how they had reached a turning point where they realized that they could not handle their situation by themselves or in out-patient care any longer, they realized their need for professional help. The alternative was by some described as either starve to death at home, die from heart failure or commit suicide as they experienced their life not worth living. Realizing having been close to death was scary, and in order to survive, they needed structure and a time-out to change their destructive lifestyle. They had surrendered, ate what the staff told them to eat and were ready to end their destructive behaviour, face their anxiety, let go of control and accept help at the ward for the time it would take to recover.

Table 1. Main theme, themes and subthemes.

Main theme	Striving with transition to a healthy life		
Themes	Struggling to find a way	A long process towards recovery	AP adds a value
Subthemes	Realizing need for help, or not Striving with weight gain Needing supportive surroundings	Getting better Getting well not just weight gain	Getting calmer Relieving somatic symptoms Bringing additional benefits Factors influencing the effect of AP

> My BMI was 10 when I was committed. I have been underweight for 20 years. I am here voluntarily, but I almost died. It was that serious. (K2)

Others had been forced into the ward. They did not realize their need for help and they had not been helped by earlier treatments. Now they were rebellious, could not adapt to the rules and did not want to be involved in anything at the ward. Although they realized they could not recover by themselves they were not motivated to search help.

> This time I'm admitted by law due to starvation and two suicide attempts last week. I have no idea what my care plan looks like. I suppose I'm to gain weight as all the other times, as all the other patients. It feels useless to force me to gain weight, I've already gained weight and come home three times, and then I had to lose weight again. I don't believe this treatment will help me. (O1)

> They do their work well but you still hate everything and everyone here. (Y1)

Some still denied the severity of symptoms and did not want to lose the subjective benefits that came with starvation, like the sensation of alertness or of getting high. As long as possible they had kept the surface, and "worked with full capacity at a demanding job until BMI 12" (Q1), and they hoped for a short stay at the clinic. As they had considered themselves rather healthy, they were surprised that the severity of their disease had rendered an immediate admittance, for some by law. Being admitted was seen as bad luck and as a trauma.

> They wanted to send me to the paediatric psychiatry, but I got away. I didn't want to, I was clever, I got away for a long time. That's why I'm under the Psychiatric Care Act now. (N1)

Striving with weight gain

Participants described that their rational side understood the necessity of gaining weight and therefore they tried to endure the strict rules for food intake. On the other hand, they hated gaining weight and the stomach pain and feeling of being stuffed and bloated that followed eating so they cheated with eating and nutritional drinks. Being forced to eat was perceived as extremely repulsive. Compared to the very limited rations before admittance, the standardized rations at the ward were perceived as huge and both the frequency, the amount and the "no-choice" of food was a challenge. They knew much about nutrition and had problems with accepting what was served without discussions. BMI was measured with two decimals, and changes in any direction were described to evoke anxiety. It took time to accept the body's change. On the one hand, eating increased anxiety, on the other hand, weight gain was the goal and opened a possibility to leave the ward. The required weight gain was one kilo/week and for those who should gain 20–25 kilo it felt long to just lay there and grow fatter.

> I was a vegan last three years for ethical reasons… I feel horrible having to incorporate animal products in my diet here. At least I don't have to eat meat. The food is creamier and spicier then what I am used to. I was always plain. Good in a way get to try new things to find what I like that I can continue later on. (U1)

Needing supportive surroundings

Patients expressed the need for support to recover, become physically stronger and to change behaviour so they could live a normal life without relapses to a destructive eating when returning home. Having tried several strategies, they now searched for tools helping them to focus on other things than weight and food and to get a better self-image, a new identity. Participants explained that learning to deal with anxiety and OCD, especially related to meals, was a core issue for recovery. They also needed support to find a balance between working out, eating and rest.

Participants described the care as shortsighted and extremely standardized: "to eat, gain weight, and prevent compensation" (X1). Early in the recovery patients were not aware of their own patient care plan and some still requested a care plan at the second interview when they had spent months at the ward. Some felt unsafe as they did not even know for how long they should stay at the ward. Participants with bad memories from earlier stays at the ward, expressed like "For every treatment I have gotten worse" (E1), described the care as "non-effective in a non-healing environment "(K1). They did not trust the staff whom they experienced to be non-supportive. Feeling no hope, they missed a more holistic view. One participant felt betrayed as she had been promised no more coercive actions, but again had been forced to eat.

To recover, patients knew they could not rely only on medication and the standard care. They knew they had to "do the work" themselves, and wanted to find new ways to approach their symptoms. They were interested in trying complementary treatment to help them relax and to pass time in a stressed environment. Those who had tried acupuncture, reflexology and massage were positive and trusted these methods to reduce anxiety, pain and cravings.

Participants described that they had lost their autonomy and that their lives were very restricted. Those admitted by law experienced that their freedom was taken away, and it took time to accept that they had to let go of their own will and let others decide about their lives. Not knowing for how long they had to be locked in against their will was scary. Others had accepted to be admitted voluntary as they knew the alternative was being admitted by law. They all knew they were forced to gain weight. Being fed by a tube was experienced as the worst situation, as was not being allowed to take a walk in the fresh air outside. Those with extra supervision suffered from being supervised 24/7, even in the bathroom. They hated to be forced to lay down still and to be transported in a wheelchair. They compared with their life before admittance when they took care of everything themselves, and were now rebellious, feeling like prisoners. In this situation, they experienced a need for support.

> I can't get a break from this environment that makes me worse, I can't eat as little as I want… I don't know their plan, I've been in a no man's land for quite long now. And I have to keep calm. If I raise my voice or cry they threaten with neuroleptic injections. (O3)

Talking to knowledgeable health care staff that they knew well was described as important support. Patients appreciated

seeing a doctor once a week, and seeing a psychologist which they could when their BMI was >16. They liked seeing the physiotherapist, and experienced that her sessions of body awareness helped them to "be in their body".

> It's easier to handle the perception of the body when you know where it ends. (Q2)

They also enjoyed the mindfulness and relaxation sessions, perceived to be more effective than the relaxation tapes available on the internet. Those who had tried art therapy described it as exceptionally helpful and regretted that it was no longer available. Participants also requested meaningful activities. Most important was talking to nurses and nurse assistants, who were always available and ready to listen. They could discuss their goals and felt hope when staff confirmed the difficulties and explained the process of recovery. Getting individualized information about AN, expected somatic changes and support to handle their OCD gave a sense of security. It was described as important to be listened to, and to hear that their thoughts and feelings were normal.

> Talks strengthening the healthy parts have helped the most. (C2)

Participants described that it took time to feel safe and trust the staff. When they had surrendered and accepted that staff decided about meals, the strict and non-negotiable rules about eating were described as a necessary structure.

> … without having people pushing you, you won't do it by yourself. (U1)

Later in the recovery, participants expressed gratitude for the care and commended the treatment that they assessed to be tough but structured and thoroughly thought through.

Sharing experiences and getting support from co-patients was considered extremely important, although sharing room with other ill persons in limited private space was challenging. Spending months together at the ward created a certain friendship and mentorship. Participants described the importance of not only sharing troubles but also laughing together. Some described how the responsibility for others' feelings and well-being, and being a role model, was both a burden and strengthening. Some were health professionals themselves and experienced difficulties in switching from their professional perspective to being a patient receiving advice.

A long process towards recovery

Participants who had proceeded in their recovery experienced the joy of getting better and they trusted in what was described as a long journey towards recovery. They knew that getting well was much more than just gaining weight and many experienced an identity crisis.

Getting better

Whilst participants had gained weight, they perceived that both mind and body regained their functions and that they were on their way of getting better. They could now remember things, were more stable, and had got used to the feeling of relaxation. They described how they earlier had refrained from eating to endure symptoms, now they could eat and yet handle anxiety and OCD. They were more aware of their feelings, could feel happiness and had gained a better understanding of food, training and of their disease. They felt they were better armed to fight the disease, and that they step by step were about to win over the anorexia. As they had more energy they could partake in social activities and they could concentrate on activities like mindfulness and reading. They had reached a turning point, felt hope and made plans for the future.

> The difference is noticeable. I am calmer and more clearheaded and think more sensibly, logically…. The "machinery" works a bit faster. When your brain is nourished everything is easier, you can use all of your resources". (K1)

> Earlier I was desperate due to being fatigued. Now I have balance to take the next step. (E2)

When BMI increased, their degrees of freedom increased. They were allowed to go out and to gradually take longer leaves of absence.

> Here you are in a protected shelter… Now I have tools to get out of this shelter, it will even be nice. (R3)

It was challenging to withstand the obvious bodily changes in terms of weight gain, although changes like being warmer and able to sleep without gloves and with only one blanket instead of three were perceived as positive.

> I had completely lost how it was to be in a healthy body. It feels awkward and unusual. … I don't recognise my body. Of course, it feels different when you've gained 15 kgs. It's tough. I can feel myself growing fast. The psychological part can't keep up. It gives me anxiety. (K1)

Participants described the struggle between their sick and healthy identity, and saw the healthy part slowly gaining territory. Although they were longing for a normal home life, some were reluctant to let their body grow and panicked when they gained weight. Some had refused to gain weight and felt no progression towards recovery, still treated by law.

> They have removed the feeding tube and decided not to force me to eat anymore. Since then I eat just enough to remain on the same weight. (O3)

Getting well not just weight gain

Patients requested more than just getting food and gaining weight. When the body grew, thoughts and feeling awaked and it became obvious that getting well was not just to gain weight. The anxiety that forced them to control so many things in their lives was seen as triggering relapse and they urged to get rid of the OCD, experienced as the most disabling symptom. They wanted to live without the safety that control brought, gain a normal relationship to food and exercise, and learn to accept a normal body. Participants feared the tipping point when they started getting rid of the disease and should build a new identity without AN. Some praised the holistic view they experienced at the clinic. Others requested "some tools for later so I'll be able to leave and go on and do a sustainable change" (V2). They

expressed that they needed a new approach towards their bodyweight and asked for help to process their sick thoughts and the underlying problems that had manifested in AN to be mentally prepared for a healthier life.

> I want to gain weight. But I also want to talk to someone about thought patterns, so that I won't get stuck in the same ones as before. I have to work a lot on my self-image. (X2)

Participants experienced that staying at the ward was "like being locked in a bubble" (L1). The structured eating at the ward was experienced as safe, food was served in exact rations and behind locked doors. Participants had not been able to change their obsessive habits by themselves and realizing that knew that the real work started when they got home and had to take to plan what and when and how much to eat, and eat it alone was seen as a frightening challenge. Earlier attempts were linked to anxiety, failure and shame. Participants described how a slippery slope had brought them back to old habits every time they had tried to handle the situation at home.

> When you go home – it's bound to be chaotic. It's a tough road to walk. I'm ready to walk now. The option would be to move in here and be served food for the rest of my life (laughter) … / Continues in a serious voice/If you can't handle the food at home you have to live here or go on being sick. It's your choice, and it's not an easy one. (E2)

This time they wished for a gradual weaning-period from the ward when they were allowed to practise the new strategies and gradually take more responsibility as they were released into the reality outside. Participants described how they during the treatment period had realized the value of relaxation and practised mindfulness and acupuncture to find the peaceful zone which they could return to and rest in, giving them a feeling of balance. They felt they were on their way out to the real world but allowed themselves time to recover.

> I have learned to stay with the anxiety instead of running from it. (H2)

Acupuncture adds a value

The informants described acupuncture to affect both body and mind, easing the struggle to get better. They expressed how it helped them in all phases of the recovery. Participants who had earlier experience of acupuncture had accepted it as soon it was offered at the clinic. Others had heard from peers that acupuncture had helped stomach problems or had seen co-patients in a peaceful rest with acupuncture needles in their ears, and were curious enough to test. Some were sceptical to alternative medicine but willing to give it a try "as I have nothing to lose" (X1). Acupuncture was described as an attractive personalized part of the treatment, a tool making it possible to influence one's own wellness. Different factors influencing the effect of the acupuncture were also described.

Getting calmer

Many participants described how acupuncture could help them relax and get into a pleasant mindful state where they could rest and be themselves, described as "it feels like getting a nice pause in your brain" (A2). They could observe and process their thoughts, one by one, without provoking stress or a compulsion to act on them. Participants described how acupuncture taught them what it felt like to be relaxed in a natural way. The effect was by some compared with that of benzodiazepines, by others as different from drugs; "not this zombielike calmness but more of a natural relaxation" (V2). They experienced that they could concentrate better and focus on issues after acupuncture. The relaxation was described as a new, deep, experience, giving them an inner peace.

> Acupuncture gives a deeper relaxation. Not a somnolent state but a recovering one. Reading a book is not recovering in the way acupuncture is. Thoughts don't shut down completely then. (P2)

The feeling of relaxation and still being present was perceived to give a picture of themselves as healthy, that was good to relate to. Thereby they found hope, and after having felt that relaxation many times they could go back to the relaxed state without needles. Even those for whom working out to compensate consumed calories had escalated to obsessive levels were surprised that they could allow themselves to sit down, or even lay still during acupuncture treatment. Participants appreciated that acupuncture motivated them to take time for relaxation, they enjoyed practicing to rest and said that time flew, 40 min with needles was experienced as five.

> You become pleasantly numb in the body. Acupuncture makes you stop for a while which gives you room to breathe and lets thoughts come and go … (C2)

> You are held by acupuncture in a peaceful situation that radiates through you, it is pleasant. Acupuncture really gives peace. It makes you endure anxiety. (C3)

The relaxation was compared to the relaxed feeling after a massage or after running, and reaching a deep relaxation was easier over time. Some described how acupuncture could help them tackle panic-attacks and "to feel less anxiety around meal times". (X2)

Statements of better and deeper sleep after acupuncture, in spite of having stopped taking sleeping pills, were made. This was perceived as valuable as lack of sleep was described as a triggering factor for their AN. Some fell asleep during acupuncture even though they normally could never allow themselves to rest during daytime.

Even participants who initially were sceptical to alternative medicine experienced an unexpected calmness that acupuncture had helped them: "The times when I received acupuncture I actually found that it became an interruption from all of the chaos" (O1). A few found it hard to relax also during acupuncture and some were uneasy with the relaxed feeling they got from acupuncture.

Relieving somatic symptoms

Compared to mindfulness acupuncture was experienced to also give physiological effects. Participants experienced their

intestines to be overloaded as they ate more and were forced to eat food they were not used to. Many described how acupuncture alleviated symptoms like stomach cramps, bloating, and intense pain that were described to be linked to gaining weight, making it easier for them to eat and relax. Participants with stubborn constipation described having an instant bowel movement after acupuncture. For some, this was the main reason to continue with acupuncture.

Acupuncture was appreciated as an alternative to pain medication, not the least by participants who avoided painkillers. Several described how acupuncture gave relief from stubborn headaches, from muscular tension arising from stress or from being freezing cold due to starvation. One participant described how the pain arising from vertebral compression due to starvation-related osteoporosis could be handled with acupuncture alone after many years on morphine. She was happy to get rid of the side effects of medication.

> Morphine made me so constipated! Now I haven't felt any pain at all. I hardly think of my stomach. (G1)

On the other hand, one participant experienced headaches from the first acupuncture treatments, not hindering her from continuing to take acupuncture.

Bringing additional benefits

Acupuncture was experienced not only to relieve anxiety and somatic complaints. Additional benefits were an undemanding moment allowing you to "let go" and indulge yourself. Participants described it as an effective distraction, a meaningful break and a relaxing free-zone isolated from the everyday life at the ward. Acupuncture was perceived as a tool the participants could use to influence their own treatment and well-being, strengthening the healthy part of one's self. It provided a feeling of getting cared for and it became "easier to accept changes and to handle the process" (Q2). Through creating harmony acupuncture was experienced to prevent relapses.

Acupuncture was perceived to give relaxation even on a bad day when the participants could not focus on other things including mindfulness or other relaxation techniques where concentration and effort were needed. Those who were treated under the Psychiatric Care Act expressed appreciation for acupuncture being a voluntary treatment. To have acupuncture to look forward to eased their restlessness.

> Acupuncture is a voluntary option in a context where you are forced and locked in. Saying "no thank you" can also be good experience … It gives you a bit of freedom to choose if you want it or not. (U1)

> To get a break from being treated against your will by a healthcare system you don't believe in. It's something to reach for. (O3)

Acupuncture was described as an attractive alternative to drugs without toxins and with fewer side effects that sometimes could replace medication. Even though medications were described to act faster and could be carried within your pocket, participants preferred acupuncture. They appreciated being calm but yet awake and focused after acupuncture.

> Medications make your brain feel like mush but acupuncture is natural. (I1)

Participants had experienced that symptoms like anxiety, muscular tension and pain interfered and increased each other in a vicious circle. When being too exhausted other problems became impossible to solve. With acupuncture the vicious circle changed direction and as one symptom decreased the others diminished, freeing energy.

Factors influencing the effect of acupuncture

The possibility to influence the treatment was experienced as very valuable. Some preferred lying down, alone, to deepen the relaxation during acupuncture and to get in close contact with the acupuncture nurse. Some preferred acupuncture before lunch, others after. Some became restless and appreciated the possibility to get a shorter treatment. Some benefitted from listening to music during acupuncture, others preferred silence. Participants also appreciated the possibility to adjust the standardized NADA protocol and get other points addressing their individual needs as well as acupressure instead of, or in addition to needles. They suggested that acupuncture could be offered in an even more individualized way addressing personal symptoms, and they wanted to continue acupuncture after being dismissed.

> I get the regular points plus one for stomach and constipation. Points to help me from what I suffer from right now. (Z1)

The individual connection with the person giving the acupuncture was described as valuable as well as the technique used when putting the needles. A continuity of acupuncture at least twice a week was perceived as more effective, an optional third time a week was appreciated but the participants needed to ask for it and not everyone dared to disturb the staff. Some described that fear of needles and fear of pain initially had hindered them to try acupuncture. For a few, pain from the needles was a helpful distraction, while for others it was something they had to get used to. The attention and getting cared for from the staff during acupuncture was also mentioned as valuable. Some experienced that adding the body-acupuncture-point GV 20 helped more than ear acupuncture alone. For some acupuncture was seen as preventive treatment; they described how acupuncture only could help if they received it before the climax of anxiety, stress and restlessness.

> The needling technique is a way to stress down during acupuncture, to breathe out when they insert the needle. It's co-work with the acupuncturist. (C1)

Discussion

AN is a complex disease with severe somatic, psychiatric and psychosocial manifestations (Fairburn & Harrison, 2003), confirmed by the participants in the present study. Their stories of different treatments during many years of illness illustrated the complexity and the long and intense suffering that came with AN. The patients expressed gratitude for the treatment program, but also a lack of an

individualized care which is worrying as this factor is important for recovery from AN (Fogarty & Ramjan, 2016; Strober & Johnson, 2012). Participants demanded personalization of treatments and to be able to make choices about their therapeutic process, which is connected to a growing feeling of well-being (Roberti di Sarsina, Alivia, & Guadagni, 2012). The treatment program was described by the participants to mainly focus on supported eating and gaining weight, supporting the findings in Stockford et al. (2019). Our informants shared how they searched for other tools to get better. They emphasized the importance of supportive surroundings, appraised acupuncture, valued encounters with the health professionals like patients in Smith et al. (2014), but requested more therapy and meaningful activities. As environmental stress increases anxiety (Strober & Johnson, 2012), adjunct treatments that like acupuncture give opportunities for relaxation (Hedlund & Landgren, 2017) might reduce anxiety and stress and thereby be beneficial for recovery (Strober & Johnson, 2012). Participants in the present study asked for support in the process of changing into new healthy identities, being able to manage their lives outside of the ward, as well as finding and engaging in meaningful activities. To perceive meaning and manageability are essential parts of one's Sense of Coherence (SoC) which has shown to be of great importance for health and quality of life (Antonovsky, 1987; Eriksson & Lindstrom, 2007). Predictability and understanding are other factors of major impact for one's SoC (Eriksson & Lindstrom, 2005). An increased partnership can increase SoC and patients' sense of control. Patients in the present study frequently described missing a patient care plan, which meant they could not predict what was going to happen to them. We remind psychiatric health care staff to carefully inform patients about their patient care plan and to repeat information and options until patients have understood what will happen and can choose to partake in optional activities. We also suggest occupational therapy, not offered at the ward where the present study was conducted, as it may assist in building a healthy identity and improve self-esteem, factors that have been mentioned in the present study as well as in a meta-analysis as important for lasting recovery from eating disorders (Stockford et al., 2019). Occupational therapy brings opportunities for persons with AN to find new ways to manage daily activities outside the ward, as well as engaging in new meaningful activities (Clark & Nayar, 2012).

In the present study, the participants described their lived experiences in different phases of recovery. Descriptions of their severe illness formed a backdrop. Having started treatment, the first theme "Struggling to find a way", encapsulating both hope for recovery and feelings of hopelessness, was transformed to the second theme "A long process towards recovery". In this theme, the participants expressed that true recovery meant a long process involving a lot more than just gaining weight. This supports research showing the need for multifaceted care that can cover somatic as well as psychological and psychosocial issues (Clark & Nayar, 2012; Fogarty & Ramjan, 2016). Needs are different in different states of recovery from AN (Fogarty & Ramjan, 2016). At a very low BMI physical health, when self-efficacy, and even lives are in danger, out-patient care is not sufficient and a higher level of care is needed (Hilbert et al., 2017; Murray et al., 2019; Strober & Johnson, 2012). Sometimes even involuntary commitment and forced feeding is necessary in order to prevent starvation to death. Providing a treatment environment characterized by warmth can reduce anxiety and be beneficial for the outcome of AN and a marked reduction of anxiety and stress early in the treatment increases the chance for restoring health (Strober & Johnson, 2012). Thus, interventions that reduce stress should be included in the treatment program. The calming effect of acupuncture (Dhond et al., 2007) experienced by participants in the present study has been described earlier by in-patients with AN (Fogarty et al., 2013; Hedlund & Landgren, 2017). Thereby acupuncture might be an interesting safe complement to usual care already early in the treatment. In this study acupuncture had been offered through the whole process towards recovery and the informants experienced that acupuncture added a value through dealing with anxiety, and easing somatic complaints which helped in the struggle to get better. In periods of high anxiety, acupuncture was above all appreciated for the calming effect. In later phases, when they stay at the ward was experienced as long-lasting and boring, acupuncture was appreciated for giving structure, entertainment, and relaxation, in line with Hedlund & Landgren (2017) where acupuncture was described "like a mental spa". Given reserved attitudes of persons with AN to new experiences (Hoetzel, von Brachel, Schlossmacher, & Vocks, 2013), an implementation of acupuncture in an eating disorder clinic may be regarded as a demanding task, so the pronounced positive evaluation of the acupuncture, from almost all participants, was remarkable.

The decreased stress and anxiety and the increased concentration ability described by the participants while receiving AP support earlier studies (Arvidsdotter, Marklund, & Taft, 2013; Dhond et al., 2007). In the present study, patients were offered acupuncture to reduce anxiety and stress, but they experienced acupuncture to reduce pain and to ease constipation and other stomach-related complaints. These experienced somatic positive side effects might physiologically be partly explained by the stimulation of the vagus nerve in the ear (He et al., 2012). The aggravation of stomach complaints described by patients when they start eating after starvation is a great obstacle for them. In the present study, the perceived positive effect from acupuncture on bowel and stomach symptoms was very welcomed by the participants as it increased their well-being and made it easier for them to go through with the rest of the treatment. This effect needs further research.

Acupuncture was well-tolerated by the participants in the present study, who described only few and mild side effects, following earlier reports (Tan et al., 2014). Acupuncture was perceived as an alternative to on-demand-medication, offering a natural, peaceful, inner state where they could stay focused, indicating that acupuncture can be an interesting adjunct to medication.

It is a challenge for nurses to keep a person-centred approach in a treatment program that is based on fixed rules and restrictions and it is an even bigger challenge to care for persons who do not want to be cared for and are forced to treatment by law. A perceived loss of autonomy related to the treatment environment was frequently expressed in the present study, both by persons who were admitted voluntarily and by law. Acupuncture was appreciated as a way to influence one's own treatment; personalized and optional in line with experiences from earlier studies (Bergdahl et al., 2014; Fogarty et al., 2013; Hedlund & Landgren, 2017; LaPaglia et al., 2016). The connection and collaboration with the nurses doing acupuncture, gave a feeling of being cared for (Fogarty et al., 2013; Hedlund & Landgren, 2017), and enhancing trust. Therapeutic talks can be very challenging and with trust issues, the possibility of receiving non-verbal care without having to open up can be comforting. Patients appreciated the small talk, and then to be left in peace and silence. For nurses, acupuncture gives an opportunity to listen and validate, thereby being a tool to build an empathic and supportive therapeutic relationship even with reluctant patients (Landgren et al., 2019), which is important in AN (Bezance & Holliday, 2013; NICE, 2017; Pemberton & Fox, 2013), also because the experience of support from the staff influences treatment satisfaction (Long, Wallis, Leung, & Meyer, 2012).

In this study, semi-standardized ear acupuncture based on the NADA protocol (Stuyt & Voyles, 2016) was used. However, while NADA is presented as a group treatment using a standardized point-protocol, most treatments in the present study were given individually and the nurses were allowed to change or add acupuncture points. Receiving acupuncture in a calm environment and the possibility to individualize the treatment by choosing certain acupuncture-points, being allowed to choose how, when, where and for how long to sit or lay down during treatment were, by our participants, considered important factors in influencing their experience of acupuncture. Acupuncture was a voluntary part of the treatment that the participants could choose to receive or to refrain from, in a situation where they in many other ways had lost their autonomy. In this study a semi-standardized protocol was chosen to emphasize an individualized approach. Individual treatments were more common as patients could choose and patients preferred to be alone. We do not know if patients' experiences had been different if the intervention should have been provided only in groups. Acupuncture was offered on schedule twice weekly, but it was also possible to receive acupuncture on demand. This flexibility to choose when to receive acupuncture was possible as there is no requirement of a license for giving acupuncture in Sweden. Contrary to an otherwise comparable study in Australia where acupuncture was provided by licensed acupuncturists who usually have no education in psychiatry and eating disturbances (Smith et al., 2014), acupuncture in the present study was provided by ordinary staff with a short ear acupuncture training, making the implementation of acupuncture smoother and cheaper. There was a shortage of nurses during the study period, and participants expressed that they sometimes had avoided asking for on-demand-acupuncture to facilitate the stressed nurses' work. Compared to body acupuncture according to traditional Chinese medicine or medical acupuncture, a semi-standardized ear acupuncture protocol offers an accessible, safe and cost-effective method which is easy to learn and to implement (Landgren et al., 2019; Tan et al., 2014). However, we do not know if body acupuncture could offer an even better experience that could motivate the use of such a more resource-intensive treatment.

Understanding patients' experiences of inpatient treatment programs through qualitative research could provide important information to improve treatment. Future quantitative studies might evaluate auricular acupuncture in other psychiatric settings, addressing effect on symptoms, the length of hospital admissions and the use of medications by auricular acupuncture.

Thrustworthiness

Credibility depends on how data were collected and covered in the emerging themes (Graneheim et al., 2017). The participants in the present study had a vast experience of being an in-patient at a ward for anorexia. We followed the participants for the length of the stay at the clinic and they were interviewed one to three times, resulting in a vast amount of data, rich in depth and in breadth, providing variations in content and multiplicity, ensuring credibility. The repeated interviews allowed a deeper understanding.

When handling this extensive data, we reminded each other of the importance of letting the informants' voices be heard and to find the most probable interpretations. In an earlier study conducted with patients at the same ward (Hedlund & Landgren, 2017), we were naïve to patients' experiences and that time chose phenomenological hermeneutic method for the inductive analysis (Lindseth & Norberg, 2004). In spite of a slightly different focus of the interviews in the present study, our pre-understanding made us choose content analysis for the analysis of the interviews in the present study. The results are described close to the informants' words to capture their life-world.

Dependability was achieved by the interactive co-operation during the long process of analysing the data and by describing the research process clearly. Extensive discussions about coding, themes, subthemes and which quotations that were most representative and suitable to include, continued until consensus was obtained. An interpretation is inevitably influenced by the researcher's personal and professional history (Graneheim et al., 2017). In the present study, the lived experience of being a patient in a ward for AN (AO) and our different professional perspectives of psychiatric nursing (KL) and occupational therapy (AO) enriched the analysis by adding different perspectives and possible interpretations to find the most probable meaning. As both authors are trained in ear acupuncture, we strived not to overestimate the participants' experiences of acupuncture. A strength is that none of us worked at the ward or were involved in the patients care.

All persons with AN who wanted to try acupuncture while being treated at a specialist clinic, voluntarily or by law, were invited to participate in the mixed methods study ACU-EAT. The present article reports the results from the qualitative part of ACU-EAT with an extra focus of patients' experiences of the acupuncture-part of the treatment. That all patients, independent of co-morbidities, were invited, gave a sample with a variety of experiences, matching clinic reality. Thus, the results may be transferable to patients with similar psychiatric symptoms treated under similar circumstances.

Conclusion

New, effective and safe therapeutic approaches for the complex disease AN are requested. As described by the participants, recovery is much more than gaining weight and a holistic perspective and person-centred care was asked for. A patient care plan is important to increase the sense of predictability. Even an effective treatment program following national guidelines, like the one in this study, can benefit from adjunctive therapies. The novelty of integrating acupuncture in psychiatric treatment makes this study interesting. Acupuncture is a complex health care intervention involving physical and emotional mechanisms, and an example of a person-centred, non-verbal, non-pharmacological method. The study adds in-depth understanding of participants' experiences of being treated for AN, and of getting semi-standardized auricular acupuncture as an adjunct to usual care. Acupuncture was appreciated, perceived to reduce anxiety and somatic complaints and may be used as adjunctive therapy in AN to improve the patient's subjective sense of well-being. Acupuncture does not cure AN but it can make every-day-life easier during a stressful treatment period.

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